Research Briefs

Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home

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Objective. To estimate the total hours of paid and unpaid personal assistance of daily living provided to adults living at home in the United States using nationally representative household survey data.

Data Sources. The Disability Followback Survey of the National Health Interview Survey on Disability (NHIS-D) conducted from 1994 to 1997.

Data Collection/Extraction Methods. Data were obtained on persons receiving help with up to 5 ADLs and 10 IADLs, for up to 4 helpers, including the activities they helped with, whether the helper was paid or not, and the number of hours of help provided in the two weeks prior to the survey. The sample consists of 8,471 household-resident adults ages 18 and older receiving help with personal assistance. About 22 percent of the sample has missing data on hours, which we impute by multiple regression models using demographic, ADL, and IADL variables.

Findings. We estimate that 13.2 million noninstitutionalized adults receive an average of 31.4 hours per week of personal assistance in ADLs and IADLs per week, with 3.2 million people receiving an average of 17.6 hours of paid help and 11.7 million receiving an average of 30.7 hours of unpaid help. More persons ages 18–64 received help than those ages 65 and older (6.9 versus 6.2 million), but working-age recipients had fewer hours (27.4 versus 35.9) per week, due in part to less severe levels of disability.

Conclusions. Personal assistance provided to adults with disabilities amounts to 21.5 billion hours of help per year, with an economic value in 1996 approaching $200 billion. Only 16 percent of this total is paid, representing $32 billion in home health services spent annually. This study, the first to estimate hours of assistance for both working-age and older adults, documents that older persons are more likely to receive paid personal assistance, while working-age people rely to a greater extent on unpaid help. This study begins to articulate the division of labor in the provision of personal assistance. Estimates of paid and unpaid hours of help by number of ADLs should inform policy concerning eligibility boundaries in long term care.

Personal assistance services (PAS)[1] with activities of daily living (ADLs) and instrumental ADLs (IADLs) are increasingly recognized as important for enabling many millions of individuals with disabilities of all ages to live in their own homes. The steady aging of the population and a strong preference for home-based services among both working-age and older persons with disabilities have likely increased the demand for PAS. However, despite the enormity of PAS as a health and welfare concern, the precise number of persons who receive such services and the hours of PAS provided to individuals living at home is not known. Existing studies are piecemeal and seldom include the full range of informal (unpaid) and formal (paid) help. Moreover, existing data pertain only to the older population, overlooking several million working-age people with disabilities who receive help in ADLs and IADLs (Kennedy and LaPlante 1997). This situation presents an obstacle to estimating the need and cost of PAS in the United States (U.S. General Accounting Office 1999).

Estimates of PAS hours vary by study, which have invariably excluded working-age recipients. An analysis of the 1996 National Survey of Caregivers, a small ($n = 1,509$) telephone survey, estimated that there were approximately 22-million U.S. households (23 percent of total households) providing an average of 17.9 hours per caregiver of informal help to individuals at least 50 years old (National Alliance for Caregiving 1997). Because most individuals have multiple caregivers, the average hours per recipient is considerably higher than this estimate.

Arno, Levine, and Memmott (1999) were interested in estimating the total hours of informal care giving nationally. They used data from two older national surveys (the 1986 Survey of Income and Program Participation and

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the 1987 and 1988 National Survey of Families and Households) yielding the number of helpers providing personal assistance, which they extrapolated to 1997 assuming that the ratio of helpers to the total population remained constant. The estimate of the number of helpers was multiplied by the estimated 17.9 hours from the 1996 National Survey of Caregivers to yield an estimated 22–26 billion hours of informal help.

A 1984–1985 study of helpers of older individuals (ages 70 and older) living in their own homes in Massachusetts found that they received an average of 34.6 hours per week of informal help (Crawford, Tennstedt, and McKinlay 1995). Boaz (1996) used the 1989 National Long Term Care Survey and the companion National Informal Caregiver Survey, and estimated that 36 hours of unpaid care giving were provided to older persons with ADL limitations on a weekly basis in 1989. Liu, Manton, and Aragon (2000), using 1994 data from the National Long Term Care Survey, estimated an average of 21.6 total hours per week of paid and unpaid help for older persons with any ADL or IADL assistance needs, including 12.6 hours of paid help per week.

In this study, we provide a statistically precise estimate of the total hours of paid and unpaid assistance provided to all adults living at home, whether or not they are older. We also measure differences in hours by age. We used data from the Disability Followback Survey (DFS), Phase II of the National Health Interview Survey on Disability (NHIS-D). Conducted between 1994 and 1997, the DFS provides the most recent national survey data covering all adults. Another aim of the study was to investigate what factors predict hours of help.

METHODS

Data

The NHIS is a nationally representative survey of U.S. households conducted annually by the Census Bureau for the National Center for Health Statistics. Respondents to the l994 and l995 NHIS also took part in two supplemental surveys, known collectively as the NHIS on Disability (NHIS-D). Phase I of the NHIS-D was designed to gather detailed data on the U.S. population with disabilities living in the community. Administered at the same time as the NHIS core, Phase I screened 126,704 adults for any indication of disability, using an extensive set of criteria, including functional limitation, specific disabling diagnoses, perception of disability, and use of disability-related services. Individuals with disabilities were later reinterviewed in Phase II for the DFS; this sample of 25,805 adults was

used for estimating hours of help. The core response rate was 94 percent, and the Phase I and Phase II response rates were 92 and 89 percent, respectively. The sample design was changed in 1995 to include more Primary Sampling Units and oversampling for Hispanics. Sampling weights were used in all estimation procedures. The Phase II weight incorporates the final core survey weight with additional corrections for nonresponse in each wave.

Survey Questions

In Phase II of the NHIS-D, adults with disabilities were asked if they had difficulty with any of seven ADLs and eight IADLs (we moved walking and getting outside from the ADL to the IADL list) and whether they received help or needed help from another person, whether hands on or supervisory. In addition, if they received such help, they were asked who helped with these activities. For each of up to four helpers, the respondent was asked which of the 15 activities the helper helped with, the relationship of the helper, whether the helper was paid and the sources for any payments, and the number of days and the average hours per day that each helper provided assistance during the past 2 weeks. We constructed a variable for the total hours of help received for each respondent by multiplying the number of days that help was received by the average hours per day and summing this over all helpers.

Imputation for Missing Data

We observed that 22 percent of those who said they were helped in the past 2 weeks did not specify either the number of days that they got help or the number of hours per day that they got help. Missing data on hours per day were more frequent than on the number of days per week.

The missing data on hours of help were nonrandom, which could produce less efficient estimates as well as biased estimates of the population parameters under study. Moreover, to produce an estimate of the total hours of help in the adult population, the missing data had to be imputed. Following Crawford, Tennstedt, and McKinlay (1995), we considered four imputation methods to handle the missing data. These methods are complete-case analysis, mean imputation, single regression model imputation, and multiple regression model imputation.

In complete-case analysis, records with missing data are ignored. In mean imputation, the average value of hours of help for nonmissing respondents is the imputed estimate. In single-regression model imputation, the predicted value from a linear regression model is the imputed estimate. However, both of these procedures treat imputed values as if they are estimated with certainty

and have no error. The last technique, multiple-regression model imputation, introduces a degree of uncertainty for each imputed estimate by adding a random component to the regression parameters (coefficients and regression variance) based on their estimated variances and replicating the imputation up to m times. Each missing value is replaced with the average of m acceptable values, representing a distribution of possibilities based on the variability of the complete cases. We employed $m = 10$, within the range that Rubin (1987) suggested.

We estimated three linear regression models for three outcome variables covering the 2 weeks prior to the survey interview: (1) hours provided by all paid helpers, (2) hours provided by a primary unpaid helper, and (3) hours provided by secondary unpaid helpers. The models can be expressed as follows:

$$Y_i = B_0 + B_1X + e_i$$

where $Y = \log$ (hours) for paid helper(s), primary unpaid helper, secondary unpaid helper(s); $X =$ vector of explanatory predisposing, enabling, and need variables; and $e_i =$ error term.

The specification of explanatory variables is provided in Table 1 along with their means and standard deviations and that of the dependent variables. The predictive variables for the models were categorized into predisposing, enabling, and need factors (Andersen 1995) and included the following: The predisposing factors were age, female, non-White race and education; the enabling factors included living alone, income, Medicare coverage, Medicaid coverage, living in an urban area, the number of paid helpers, and the number of unpaid helpers. The need factors were 5 ADLs (bathing, dressing, transferring, toileting, and eating) and 10 IADLs (such as grocery shopping, walking, meal preparation, light housekeeping) specified as (0,1) dummy variables. These variables indicate, for each of the three sources of help, whether the respondent was helped in that activity. A significant effect means that help with that particular activity increased or decreased total hours of help received by that class of helper. The model measures the independent effects of these activities that are generally correlated. These explanatory variables were selected based on previous studies of formal and informal long-term care.

The imputation procedure is described as follows:

1. Estimate a linear regression model using complete data cases only. Let $\hat{\beta}_{cca}$ and $\hat{\sigma}^2_{cca}$ be the estimated regression coefficient vector and the estimated regression variance in complete case analysis (cca).

Table 1:   Descriptive Statistics on Hours of Personal Assistance and for Explanatory Variables Used to Predict Hours Among Populations with Any Helper(s), Paid Helper(s), a Primary Unpaid Helper(s), and Secondary Unpaid Helper(s)

	Population with helper(s)		Population with paid helper(s)		Population with primary unpaid helper		Population with secondary unpaid helper(s)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Explanatory variables								
Predisposing factors								
Female = 1	0.65	(0.60)	0.70	(0.57)	0.64	(0.60)	0.70	(0.57)
Non-White = 1	0.17	(0.47)	0.14	(0.43)	0.17	(0.47)	0.21	(0.50)
Age (continuous, 18–99)	60.57	(23.31)	69.51	(20.77)	59.66	(23.35)	58.96	(23.92)
Education (continuous, 0–18)	10.80	(4.62)	11.12	(4.76)	10.72	(4.55)	10.38	(4.68)
Enabling factors								
Living alone = 1	0.24	(0.53)	0.46	(0.62)	0.20	(0.50)	0.22	(0.51)
Monthly income ($1,000s, continuous)	0.90	(1.21)	1.05	(1.26)	0.87	(1.17)	0.77	(1.01)
Medicare = 1	0.62	(0.61)	0.80	(0.50)	0.60	(0.61)	0.58	(0.61)
Medicaid = 1	0.26	(0.55)	0.27	(0.55)	0.26	(0.55)	0.29	(0.56)
Urban = 1	0.73	(0.56)	0.73	(0.55)	0.73	(0.56)	0.71	(0.56)
Number of paid helpers (0–4)	0.30	(0.75)	1.25	(0.68)	0.17	(0.58)	0.15	(0.52)
Number of unpaid helpers (0–4)	1.30	(1.06)	0.72	(1.01)	1.47	(0.94)	2.39	(0.79)
Need factors								
Person receives help in ADLs								
Bathing = 1	0.29	(0.57)	0.41	(0.61)	0.24	(0.53)	0.14	(0.42)
Dressing = 1	0.23	(0.52)	0.30	(0.57)	0.20	(0.50)	0.14	(0.43)
Transferring = 1	0.18	(0.48)	0.22	(0.51)	0.18	(0.47)	0.15	(0.44)
Toileting = 1	0.10	(0.37)	0.16	(0.45)	0.09	(0.36)	0.08	(0.34)
Eating = 1	0.07	(0.32)	0.12	(0.40)	0.06	(0.31)	0.06	(0.30)

IADLs

Walking = 1	0.22	(0.52)	0.24	(0.53)	0.22	(0.51)	0.19	(0.48)
Getting outside = 1	0.26	(0.55)	0.32	(0.58)	0.25	(0.54)	0.23	(0.52)
Preparing meals = 1	0.35	(0.60)	0.37	(0.60)	0.33	(0.59)	0.26	(0.54)
Shopping for groceries = 1	0.56	(0.62)	0.57	(0.61)	0.55	(0.62)	0.48	(0.62)
Managing money = 1	0.23	(0.53)	0.27	(0.55)	0.23	(0.52)	0.13	(0.42)
Using telephone = 1	0.10	(0.38)	0.13	(0.42)	0.10	(0.37)	0.08	(0.33)
Doing heavy housework = 1	0.75	(0.54)	0.83	(0.47)	0.63	(0.60)	0.57	(0.61)
Doing light housework = 1	0.38	(0.60)	0.49	(0.62)	0.31	(0.58)	0.32	(0.57)
Getting to places outside = 1	0.47	(0.62)	0.50	(0.62)	0.45	(0.62)	0.47	(0.62)
Managing medication = 1	0.21	(0.50)	0.29	(0.56)	0.19	(0.49)	0.13	(0.41)
n	8,471		2,043		7,505		2,611	
Weighted (1000s)	13,172		3,154		11,660		3,965	
Dependent variable								
Hours of help received in past 2 weeks (continuous, 0–504)	30.9	(65.5)	19.1	(48.8)	25.5	(52.9)	16.4	(41.0)
n	6,637		1,686		5,489		2,052	
Percent missing on the dependent variable	22		17		27		21	

2. Draw a χ^2_{n-p} random variable k^*, and let

$$\hat{\sigma}^{2*} = \hat{\sigma}^2_{cca} \times (n-p)k^*,$$

where n is the number of complete data cases, and p is the number of regression coefficients.

3. Add a number randomly drawn from $N(0,1)$, z^*_j, to the jth regression coefficient, $\hat{\beta}^{(j)}_{cca}$,

$$\hat{\beta}^{(j)} = \hat{\beta}^{(j)}_{cca} + \hat{\sigma}^*(s^{(j)}_{cca}/\hat{\sigma}_{cca})z^*_j, \quad j = 1, \ldots, p,$$

where $s^{(j)}_{cca}$ is the standard error of the jth regression coefficient from step 1.

4. A new imputed value for missing data is computed as

$$Y^*_i = X_i\hat{\beta}^* + \hat{\sigma}^*z^*_i, i = 1, \ldots, n_1,$$

where z^*_i is a random number drawn from $N(0,1)$, and n_1 is the number of missing data.

5. Repeat steps 2 through 4 m times. The final imputed value $\hat{Y}^*_i$ for missing data Y_i is computed as

$$\hat{Y}^*_i = \sum_{k=1}^m Y^*_{ik}/m, i = 1, \ldots, n_1$$

As the sample distributions of paid hours and unpaid hours were skewed toward high values, we fitted the regression models on the logarithm (natural) of hours. Missing values imputed on the logarithmic transformed scale were retransformed to the original scale using a nonparametric method in order to achieve unbiased and consistent quantities on the original scale (Duan 1983). The final results presented in this article are based on the multiple regression model imputation. Empirically, the multiple regression model imputation provided a statistically more satisfactory set of results, with the outcome variable being more normally distributed than the other methods. Further details of the multiple regression model imputation are given in Rubin (1987) and in Crawford, Tennstedt, and McKinlay (1995).

Analysis

We discovered that the hours for the primary unpaid helper (the first-listed unpaid helper if more than one was mentioned) had to be estimated separately from the hours for the secondary unpaid helpers because the predictors were

different. Moreover, we found that different factors were associated with paid versus unpaid help. Approximately 17 percent of paid hours were missing, as were 27 percent of unpaid hours provided by the primary helper, and 21 percent of unpaid hours provided by the secondary helpers. These three models individually performed better than a model that predicted total hours. To facilitate comparison across the three outcome variables, we included the same predictors in all three models, deleting those variables that were not significant in any. Medicaid coverage was included as a complement to Medicare coverage, despite lack of significance. The complete set of ADL and IADL variables was included for comparison, although transferring, toileting, and managing money were not significant in any model.

Variance Estimation

The NHIS-D employed a complex (i.e., nonrandom) sample design that involved multiple stages of selection with a high degree of stratification and clustering. Because of this sampling design, individual responses are correlated (Lee, Forthover, and Lorimor 1989). We used SUDAAN software to adjust for this nonrandomness for both point and regression estimates using Taylor linearization.

RESULTS

The sample included 8,471 individuals representing a total population of 13.2-million persons who needed or received help with ADLs/IADLs in the 2 weeks prior to being interviewed (Table 1).[2] As expected, most people received informal or unpaid help. Help from one or more paid helpers was received by 3.2-million persons (23.9 percent); 11.7-million persons received help from a primary unpaid helper (88.5 percent), which tended to be a spouse or often a parent, and 4.0 million (30.1 percent) received additional help from one or more secondary unpaid helpers, often children and friends. Of all recipients of help, 65 percent were female, and 17 percent were non-White. The average age was 60.6 years—6.9-million working-age persons (18–64 years) and 6.2-million older persons (65 years and over). The average education was just under completion of the eleventh grade. Almost a quarter (24 percent) lived alone. Sixty-two percent had Medicare. Twenty-six percent had Medicaid, and 73 percent lived in urban areas. On average, recipients had 1.6 helpers, 0.3 paid and 1.3 unpaid. Those who received paid help were 69.5 years old—almost 10 years older than those who received unpaid help—and they were more likely to

live alone, have higher incomes, to be on Medicare, to be helped with ADLs, and to be helped with housework. People who got help from one or more secondary unpaid helpers were less likely to be helped with bathing and dressing than those who got help from a primary unpaid helper but were about as likely to be helped with other ADLs and IADLs.

In order to impute missing hours, we estimated linear prediction models for the three sources of hours of help. Table 2 shows the estimated multiple regression imputation models for the log of paid hours of help and hours provided by unpaid primary and secondary helpers. The model for paid hours accounted for 44.3 percent of the variation, adjusted for the number of predictor variables. Being non-White, living in an urban area, and the number of paid caregivers were positive predictors of paid hours of care, whereas the number of unpaid helpers was a significant negative predictor. Thus, the greater the number of informal helpers a person has, the lower the hours that are provided by paid helpers—the more paid helpers, the more paid hours. With respect to the need factors, these models predict the number of hours that each individual received based on the activities that the particular class of helper(s) actually helped with. The coefficients represent the independent effects of each activity. Bathing was the only ADL factor that was a significant predictor of paid hours, in the positive direction. Six IADLs were significant positive predictors of paid hours, with the strongest factor being help in preparing meals. One IADL—receiving heavy housework—was a negative predictor of paid hours of care. Heavy housework is the most common activity in which people get help, and it represents the group with the lowest level of disability.

The model for hours provided by the primary unpaid helper was different from the paid helper model. Non-White persons had higher unpaid hours, as they did for paid hours, and the number of unpaid caregivers had a negative association with hours received from the primary unpaid helper. Thus, the greater the number of informal helpers that a person has, the lower the hours that are provided by the primary informal helper. Unlike paid hours, the number of paid helpers was not associated with informal hours. As with paid hours, age had no impact. However, being female, having higher levels of education, living alone, and having a higher monthly income were negative predictors of unpaid hours, and Medicare was a positive predictor, although none of these variables were significant predictors of paid hours. As with paid hours, getting help with bathing was significant. Dressing and eating had no effect on paid hours but were associated with greater unpaid hours. Walking and getting outside were two IADLs that increased unpaid hours, but not paid

Table 2: Estimated Weighted Regression Models for the Log Hours of Personal Assistance Services Among Populations with Paid Helper(s), a Primary Unpaid Helper, and Secondary Unpaid Helper(s)

	Population with Paid Helper(s)		Population with a Primary Unpaid Helper		Population with Secondary Unpaid Helper(s)	
	Coefficient (SE)†					
Predisposing factors						
Female = 1	0.063	(0.057)	−0.109**	(0.029)	0.011	(0.046)
Non-White = 1	0.175*	(0.087)	0.089*	(0.039)	0.162**	(0.057)
Age (continuous, 18–99)	0.001	(0.003)	0.001	(0.001)	−0.004**	(0.001)
Education (continuous, 0–18)	−0.009	(0.007)	−0.013**	(0.004)	−0.029**	(0.006)
Enabling factors						
Living alone = 1	0.032	(0.056)	−0.643**	(0.031)	−0.459**	(0.054)
Monthly income ($1,000s, continuous)	0.028	(0.024)	0.034*	(0.015)	0.022	(0.029)
Medicare = 1	−0.064	(0.085)	0.093**	(0.034)	−0.011	(0.052)
Medicaid = 1	0.104	(0.081)	0.010	(0.032)	0.067	(0.051)
Urban = 1	0.183**	(0.063)	0.038	(0.034)	0.042	(0.054)
Number of paid helpers (0–4)	0.360**	(0.059)	0.020	(0.030)	0.058	(0.058)
Number of unpaid helpers (0–4)	−0.345**	(0.042)	−0.045*	(0.020)	0.304**	(0.036)
Need factors						
Person receives help in:						
ADLs						
Bathing = 1	0.261**	(0.092)	0.304**	(0.039)	0.356**	(0.094)
Dressing = 1	0.091	(0.119)	0.155**	(0.047)	0.108	(0.093)
Transferring = 1	0.133	(0.114)	−0.032	(0.047)	−0.026	(0.079)
Toileting = 1	0.142	(0.129)	−0.016	(0.057)	−0.177	(0.125)
Eating = 1	0.171	(0.131)	0.215**	(0.068)	0.144	(0.131)
IADLs						
Walking = 1	0.141	(0.095)	0.260**	(0.038)	0.442**	(0.075)
Getting outside = 1	−0.015	(0.083)	0.199**	(0.044)	0.323**	(0.057)
Preparing meals = 1	0.596**	(0.084)	0.669**	(0.035)	0.474**	(0.060)
Shopping for groceries = 1	0.210**	(0.065)	0.141**	(0.029)	0.132**	(0.048)
Managing money = 1	0.052	(0.084)	0.002	(0.037)	−0.007	(0.077)
Using telephone = 1	0.253*	(0.112)	0.276**	(0.055)	0.097	(0.114)
Doing heavy housework = 1	−0.235*	(0.091)	0.070*	(0.032)	0.064	(0.047)
Doing light housework = 1	0.269**	(0.061)	0.302**	(0.035)	0.369**	(0.058)
Getting to places outside = 1	0.155*	(0.064)	0.295**	(0.028)	0.057	(0.048)
Managing medication = 1	0.242*	(0.099)	0.467**	(0.044)	0.353**	(0.082)
Intercept	1.318**	(0.221)	2.200**	(0.083)	1.629**	(0.144)
n	2043		7505		2611	
Weighted *n* (1000s)	3154.1		11660.3		3965.0	
Regression variance	1.488		1.436		1.513	
R^2	0.450		0.512		0.405	
Adjusted R^2	0.443		0.511		0.399	

*Statistically significant at $p < 0.05$.

**Statistically significant at $p < 0.01$.

†Standard error estimated using SUDAAN software.

hours. As with paid hours, preparing meals had the largest effect on unpaid hours. This model explained 51 percent of the variance.

The model for secondary unpaid hours was different from the model for primary unpaid helper hours. Being non-White was more strongly significant. Older persons received fewer hours from secondary unpaid helpers. This is the only model in which age had any effect on hours. People with higher education and those who lived alone received fewer secondary hours, whereas the number of unpaid helpers was a positive factor. Bathing was a significant positive factor, but unlike for primary helper hours, dressing and eating were not significant. Preparing meals and walking were the strongest IADL factors, followed by light housework, managing medication, and getting outside. The model for unpaid secondary hours explained slightly less variance than the other two models (40 percent). In both unpaid models, living alone had a very large impact with an absolute effect as large as that of help with meal preparation, the strongest of the need (ADL/IADL) predictors. Walking and getting outside increased hours of unpaid help, especially among secondary unpaid helpers.

The final results of the imputation on the estimated total hours, which is the sum of the hours over the three populations, are shown in Table 3. The mean hours per person were 30.9 for the known cases and 31.4 for the multiple regression model imputation method. The greatest difference was for paid hours. The multiple regression model imputation method produced an estimate of 17.6 hours compared with 19.1 for the known cases. This resulted because, of those who received paid services, the missing data were more likely among those with less disability, which the regression model adjusts for.

Table 4 shows the total paid and unpaid hours, including the imputed data, for all persons receiving help. Those who received paid help got 17.6 hours of paid help, and those who received unpaid help got 30.7 hours of unpaid help per week. Thus, although the minority of recipients got paid help, they also got lower hours of paid help than unpaid help.

Those who get help with any ADLs average 57.0 hours of help per week. The 8.3-million people who do not receive help with ADLs but received help with any of the IADLs received just 16.3 hours per week. The total hours of help increased from those needing help in bathing receiving an average of 63.6 hours per week to those needing help in eating receiving 106.7 hours. Unpaid hours increase more with the number of ADLs and IADLs a person gets help with than do paid hours. Of persons getting help with five ADLs, those who get unpaid help get 108.7 unpaid hours, and those who get paid help get 50.8 paid hours.

Table 3: Estimated Means and Standard Deviations of Hours of Assistance in ADLs/IADLs for Respondents with Known Hours and Including Imputed Hours

	Mean total hours	(SD)	N	Number (1000s)	Mean paid helper hours	(SD)	N	Number (1000s)	Mean unpaid primary helper hours	(SD)	N	Number (1000s)	Mean unpaid secondary helper hours	(SD)	N	Number (1000s)
Known hours only	30.9	65.5	6,637	10,272	19.1	48.8	1,686	2,597	25.5	52.9	5,489	8,509	16.4	41.0	2,052	3,106
Known and imputed hours	31.4	63.2	8,471	13,172	17.6	45.2	2,043	3,154	25.1	49.7	7,505	11,660	16.6	39.0	2,611	3,965

Note: Mean total hours are estimated as the sum of paid hours and unpaid hours divided by the total number of recipients of help.

Table 4: Estimated Paid, Unpaid, and Total Hours of Personal Assistance Services Provided to Adults Living at Home

	All hours per week		Paid hours per week		Unpaid hours per week		Number receiving paid care as percent of total (percent)
	Mean	Number (1000s)	Mean	Number (1000s)	Mean	Number (1000s)	
ADLs							
Bathing	63.6	3,998	30.9	1,295	59.2	3,617	32.4
Dressing	70.9	2,988	34.9	895	65.6	2,753	29.9
Transferring	73.1	2,404	39.0	696	66.5	2,236	29.0
Toileting	98.2	1,473	43.9	549	90.7	1,328	37.3
Eating	106.7	1,062	47.5	416	98.6	949	39.2
Any ADL	57.0	4,892	30.4	1,392	52.8	4,482	28.5
# of ADLs							
0	16.3	8,280	7.5	1,762	16.9	7,178	21.3
1	29.5	1,903	21.5	457	26.7	1,739	24.0
2	45.8	983	17.2	241	44.8	913	24.6
3	59.6	674	27.4	176	56.4	627	26.1
4	85.9	629	37.2	208	79.6	582	33.0
5	118.5	704	50.8	311	108.7	622	44.1
IADLs							
Walking	68.8	3,067	32.9	888	64.2	2,834	29.0
Getting outside	67.1	3,489	31.1	1,108	62.1	3,217	31.7
Preparing meals	57.2	4,213	31.2	1,089	53.3	3,886	25.9
Shopping for groceries	41.5	6,732	23.0	1,655	38.8	6,216	24.6

Managing money	62.0	2,697	32.7	782	57.1	2,478	29.0
Using telephone	87.2	1,337	47.6	429	79.6	1,208	32.1
Doing heavy housework	30.5	9,102	15.6	2,392	30.3	7,944	26.3
Doing light housework	53.8	4,271	27.1	1,258	50.9	3,848	29.5
Getting to places outside	46.3	6,281	24.5	1,679	43.2	5,777	26.7
Managing medication	71.2	2,533	35.6	823	66.1	2,284	32.5
Any IADL	31.7	12,807	17.6	3,114	31.1	11,325	24.3
# of IADLs							
0	19.9	365	22.4	40	19.1	335	10.9
1	10.4	4,052	4.9	899	11.3	3,315	22.2
2	21.8	2,269	11.0	505	21.9	2,006	22.2
3	26.4	1,618	18.3	358	24.1	1,501	22.1
4	31.8	1,220	19.7	242	29.6	1,151	19.9
5	34.3	961	14.9	211	33.0	904	21.9
6	48.3	711	21.7	203	46.0	651	28.5
7	59.6	725	25.3	219	56.8	662	30.3
8	71.7	462	34.1	154	66.4	420	33.4
9	94.1	334	33.7	121	88.4	309	36.1
10	128.0	455	54.2	203	116.7	405	44.5
Any IADL/ADL	31.4	13,172	17.6	3,154	30.7	11,660	23.9

n = 8,471 cases (13.2-million persons weighted)

More than 9-million individuals received help with heavy housework, but these individuals received the fewest hours (30.5 hours per week) compared with the other IADLs.

The fewest number of persons (1.3 million) received help with using the telephone, but they received an average of 87.2 total hours of help per week, the highest number of hours of the IADLs.

DISCUSSION

This is the first study to estimate the total hours of PAS provided to adults living in the community. Based on a large national survey covering all adults 18 years and older, we found that 13.2-million adults received help in ADL/IADLs, averaging 31.4 hours per week. This amounts to 21.5 billion hours of PAS help per year, of which 13.4 percent is paid and the remainder is unpaid. If paid hours are valued at the wage rate of the average home health worker at $11 per hour in 1996, the market value of home health services would be roughly $32 billion a year. This estimate is identical to another independent estimate of national home health expenditures (Levit et al. 1997). This study estimated the total hours of informal help at 18.7-billion hours, somewhat less than the 22- to 26-billion estimated by Arno et al., who relied on the average number of hours for family caregivers taken from one survey and multiplied by the number of helpers from two other surveys, projected into the future. The advantage of this study is that we estimate this number directly from a large national survey. The market value of informal PAS is approximately $166 billion if the 18.7-billion hours are likewise valued at $9 per hour, which is above the minimum wage but less than the wage of a home health worker.

Moreover, we can disaggregate these estimates by age. Although working-age (18–64 years old) PAS recipients outnumber older recipients (6.9 vs. 6.2 million), they receive fewer hours of help (27.4 vs. 35.9 hours per recipient per week). This results in a total of 9.9-billion hours provided to working-age people with disabilities compared with 11.6 billion provided to the older population. Although the hours of paid help are the same for working-age and older recipients, the majority (70 percent) of recipients of paid help are older. Thus, of the $32 billion in paid help provided annually, $9.3 billion is provided to working-age people with disabilities and $23.7 billion to older people with disabilities.

Although it is beyond the scope of this article to assess fully the potential disparities in PAS by age, we note that the mean number of ADL/IADLs was

somewhat higher for older recipients (mean of 4.67 vs. 3.81). Because hours of care increase steadily with the number of ADL/IADL dependencies, a crude adjustment of hours for differences in ADL/IADL dependencies can be made by simply dividing the mean hours by the mean number of ADL/IADLs. This reveals that working-age recipients received 7.2 hours per ADL/IADL compared with 7.7 hours for older recipients. Alternatively, if we adjust by the mean number of ADLs in the two age groups (0.8 for 18–64, 1.05 for 65+), we obtain 35.3 and 34.2 hours per ADL limitation. Thus, the lower mean hours among working-age PAS recipients is partly due to having fewer ADL/IADL dependencies. In any case, this study clearly shows that health and welfare policy must comprehend that long-term care is, at this point in time, much more than a problem of just the older population.

A recent study by Liu, Manton, and Aragon (2000), based on the National Long Term Care Survey, estimated that 4.0-million older persons (65 years and older) received a total of 25.4 hours[3] of help per week, including 12.6 hours of paid help, in 1994. We obtain both a higher number of older recipients (6.2 million) and higher average hours per recipient (35.9 hours total, 17.9 hours of paid help). One difference is that the National Long Term Care Survey used a 1-week reference period, whereas the NHIS-D used a 2-week reference period, which is likely to capture a greater number of recipients because helping is to some degree episodic. Also, data on recipients and hours were obtained in Phase II of the NHIS-D, which occurred from 7 months to up to 26 months (median of 13.6 months) after individuals were first screened in on the basis of any level of disability. The number of recipients getting help with ADL/IADLs was higher in Phase II than in Phase I. It is possible that individuals previously screened would have become more disabled as time progressed, which would tend to increase the number of recipients and possibly the average hours of help. However, we found that the number of individuals was higher in Phase II, regardless of the length of time that expired between interviews. It is possible that the DFS questionnaire and procedures identified more recipients and hours. Although these differences in the older population are important, they require additional analyses to isolate the reasons why. Nevertheless, the findings we report are within the range identified in the literature.

We found that the need factors (ADLs and IADLs) were the most important predictors of hours of help. In all the models examining paid and unpaid hours of help, bathing was the most important ADL measure in predicting hours, controlling for other ADLs and IADLs for which help was received. Controlling for disability and other factors, age was of little importance. However, living alone had a substantial negative impact on unpaid hours, even

adjusted for the number of helpers, and rivaled the effects of the strongest need factors. This suggests that informal providers fail to provide as many hours of help to people who live alone, independent of their disability needs. All of the models explained a high degree of the variation in hours, from 40 to 51 percent.

This study offers some evidence that informal help substitutes for formal help. The greater the number of informal helpers that are available, the lower the hours that are provided by paid helpers. The number of paid helpers had no impact on informal hours, however. The number of unpaid caregivers also reduced the amount of care provided by the first helper. The presence of additional informal caregivers, often children, reduces the hours provided by the primary caregiver, which is often the recipient's spouse.

We found that the predictors of paid and unpaid hours are different. Paid hours were somewhat less predictable by the variables tested than were unpaid hours. Paid hours are often constrained by budget caps, which are not measurable. Unpaid hours were predicted by a greater number of ADL/IADL activities, particularly help with mobility, and whether recipients lived alone. As we know, informal hours depend particularly on the availability of family and friends who appear to be more likely to spend time helping with many activities that paid helpers are less likely to assist with, such as walking and getting outside. This study begins to articulate the division of labor in the provision of personal assistance.

Overall, the study demonstrated that the paid and unpaid hours increase rather dramatically as the number of ADLs and IADLs increase, as would be expected. Having more precise estimates of total paid and unpaid hours of care in the United States for different levels of ADLs and IADLs should provide some guidelines for planners and policy makers who are attempting to address the needs of different types of disabled populations. The findings also showed that the amount of paid care is dramatically less than the unpaid care provided by helpers, representing only 13.4 percent of the total hours of PAS. This understanding may be useful for policy makers who would like to expand the amount of paid care provided to individuals with ADL and IADL limitations. Future studies could use these estimates to model the costs of expanding paid coverage for different levels of care, disability groups, and income groups.

NOTES

1. We prefer the term *personal assistance* over *long-term care*. The term *care* is often equated with help for those who are sick or frail. Many people, particularly those

who are not older, who need assistance with ADLs and IADLs, are neither sick nor frail.
2. A weighted 2-million people said that they got help with these activities, but not in the past 2 weeks. They are not included in this analysis.
3. The estimate reported by Liu, Manton, and Aragon (2000) is 21.6 hours, but the denominator includes 0.7-million older persons who did not get help during the survey reference week. Because our study excluded people who did not get help in the NHIS-D reference period, we recomputed Liu et al.'s mean hours excluding this group.

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